



Access to and use of health and social care services for people with learning disabilities during COVID-19: a longitudinal study

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Abstract**Purpose**

This paper presents data about access to, and use of, health and social care services by adults with learning disabilities during the COVID-19 pandemic in England, Northern Ireland, Scotland and Wales.

Methodology

Data were collected in three Waves between December 2020 and September 2021 and concerned the use of health and social care services during the COVID-19 pandemic. Data were collected at one or more time-points directly from 694 adults with learning disabilities and through separate proxy reports by family carers and paid support staff of another 447 adults with learning disabilities.

Findings

Many people with learning disabilities who reported regularly accessing services/supports pre-pandemic were not receiving them during this study. There were indications of increasing access to some services and supports between Wave 2 and 3, but this was not universal.

Implications

People in Cohort 2, who were likely to have severe/profound learning disabilities, were less frequently reported to access online community activities than people in Cohort 1, which is likely to exacerbate existing social isolation for this cohort, and their family carers. Service providers should seek to ensure equitable access to services and activities for all people with learning disabilities in the event of future lockdowns or pandemics.

Originality

This is the largest longitudinal study about the impact of the COVID-19 pandemic on health and social care services for adults with learning disabilities in the UK. We primarily collected data directly from adults with learning disabilities, and worked with partner organisations of people with learning disabilities and family members throughout the study.

Key words: learning disabilities, health, social care, access to services, COVID-19

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Introduction

This paper will explore whether there were trends in the access to and use of health and social care services by people with learning disabilities at three timepoints during the COVID-19 pandemic (between March 2020 and September 2021).

Large-scale surveys about people's lives and experiences during the COVID-19 pandemic have tended to use methods (e.g., online surveys) that are likely to either exclude or not identify people with learning disabilities (e.g., Understanding Society, 2021). Even nationally representative surveys are likely to have insufficient numbers of people with learning disabilities to enable meaningful analysis (Totsika et al., 2021), and may not ask questions of specific relevance to people with learning disabilities. Thus, there is a risk that the experiences of people with learning disabilities across the UK are not well represented in discussions about the impact the pandemic has had.

There are some limited data concerning access to health and social care services for adults with learning disabilities in the UK during the pandemic, which suggest reduced use of health and social care services (Mencap, 2020; The Scottish Commission for People with Learning Disabilities, 2020). However, these surveys have tended to be cross-sectional and largely completed by family carers of people with learning disabilities alone (e.g., Mencap, 2020), and without the capacity to explore these data longitudinally.

Our *Coronavirus and people with learning disabilities study* (2021) sought to address these issues by directly collecting data from adults with learning disabilities using direct interview methods wherever possible, focussing on key issues (including access to health and social care services) that were highlighted as being important by partner organisations involving people with learning disabilities. It was also designed to gather longitudinal data, collected at three timepoints, to allow the examination of access to and use of health and social care services.

Dataset

The *Coronavirus and people with learning disabilities study* (Flynn et al., 2021a) consisted of three Waves of data collection from across the UK, using direct interviews with 694 adults with learning disabilities (Cohort 1) at one or more timepoints. During the same periods, we also conducted an online survey of family carers and paid support staff of 447 adults with learning disabilities who could not take part in an interview with a researcher themselves (Cohort 2) at one or more timepoints. In most instances, the individuals reported about in Cohort 2 were likely to have severe/profound learning disabilities (although we do not have direct information about these individuals' level of learning disability); a group with high support needs who were unlikely to be represented in any large-scale experience surveys. Adults were defined as being aged 16 years and over in England, Scotland and Wales, and 18 and over in Northern Ireland.

The first Wave of data collection took place between December 2020 and February 2021, Wave 2 data collection was between April and May 2021, and Wave 3 data were collected between July and August 2021. There were a variety of questions about aspects of life during the COVID-19 pandemic (e.g., mental health, COVID-19-related questions, access to services, social contact). Full details of the survey methods and participants can be found in Flynn et al. (2021a). The data presented in this paper focus on the use of health and social care services at three timepoints during the COVID-19 pandemic, between March 2020 and September 2021. The results presented below are only from participants whose data were collected at Wave 1 and at Wave 2 and/or Wave 3 of this study to allow

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for comparisons between service/support access pre-pandemic (Wave 1 data) and service/support access during the latter two waves of data collection. At Wave 1, for participants in Cohort 2, there was an option to select “Don’t know” when asked about whether the person they support regularly saw each healthcare professional (GP, community nurse, psychiatrist/psychologist/counsellor, other therapist) pre-pandemic. “Don’t know” responses are not included in the tables below, but never exceeded 2% of the responses.

Results from the first Wave of data collection were reported previously (Flynn, Hatton, and the Coronavirus and people with learning disabilities study team, 2021).

Results

Pre-pandemic use of health and social care services

For all the adults with learning disabilities included in both study cohorts, Table 1 reports the number and percentages of people who reported that they were regularly seeing different health and social care professionals or accessing services and supports before March 2020. These data are drawn from Wave 1 of the study.

****INSERT TABLE 1 ABOUT HERE****

In Cohort 1, participants most frequently reported regularly accessing community activities (75.9%), having personal assistants/support workers help them at home (49.3%), going out with personal assistants/support workers (44.2%), and seeing their GP (38%) before the pandemic began (in March 2020). The least frequently reported professionals or services to be seen or accessed pre-pandemic were respite or short breaks (9.4%), other therapists (e.g., speech and language therapist, physiotherapist) (13.1%), and further education (15.1%).

In Cohort 2, participants reported that the person they support/care for was most frequently accessing community activities (65.5%), going out with personal assistants/support workers (58.8%), going to day services (47.7%), and having personal assistants/support workers help them at home (47.0%) before the pandemic began. The least frequently reported professionals or supports being seen or accessed pre-pandemic for this cohort were further education (18.6%), psychiatrists/clinical psychologists/counsellors (20.8%), and community nurses (24.6%).

Comparatively, pre-pandemic, people in Cohort 1 more frequently reported accessing community activities compared with people in Cohort 2 (75.9% vs. 65.5%), but the converse was apparent for accessing day services (32.1% vs. 47.7%), going out with personal assistants/support workers (44.2% vs. 58.8%), accessing respite or short breaks away from home (9.4% vs. 30.6%), and seeing other therapists (e.g., speech and language therapists, physiotherapists) (13.1% vs. 28.6%).

Access to health and social care services and formal supports over time for people who used the services pre-pandemic

For all the adults with learning disabilities included in both cohorts who reported regularly using each service or seeing professionals pre-pandemic, Table 2 reports how many had received these formal supports in the four weeks before their interview/survey during the Wave 2 (April-May 2021) and Wave 3 (July-August 2021) data collection periods.

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****INSERT TABLE 2 ABOUT HERE****

There was a substantial proportion of participants in both cohorts who reported regularly receiving services and supports from professionals pre-pandemic who reported not receiving them at all (neither in person, via the telephone, or online) during Wave 2 and Wave 3 of the study. Notably, the majority of participants in Cohort 1 who were seeing these professionals regularly pre-pandemic reported, at Wave 2 and Wave 3 of the study, not seeing their GP (Wave 2: 53.3%; Wave 3: 53.7%), community nurse (Wave 2: 62.5%; Wave 3: 62.1%), psychiatrist/clinical psychologist/counsellor (Wave 2: 73%; Wave 3: 66%), their other therapist (e.g., speech and language therapist, physiotherapist) (Wave 2: 72%; Wave 3: 81.7%), or social worker (Wave 2: 60.7%; Wave 3: 60.3%) at all in the four weeks before their interview. Similarly in Cohort 2, the majority of participants in this sub-group reported not seeing their community nurse (Wave 2: 55.6%; Wave 3: 54.4%), psychiatrist/clinical psychologist/counsellor (Wave 2: 60.7%; Wave 3: 70%), their other therapist (e.g., speech and language therapist, physiotherapist) (Wave 2: 55.7%; Wave 3: 54.1%), or social worker (Wave 2: 83.5%; Wave 3: 64.8%) at all in the four weeks before their interview.

In terms of accessing services during the same timeframes, the majority of participants in Cohort 1 who reported regularly receiving these services and supports pre-pandemic also reported not having accessed a day service (Wave 2: 54%), or respite or short breaks away from home (Wave 2: 85.7%; Wave 3: 67.6%). Similarly for this sub-group of participants in Cohort 2, the majority were reported to have not accessed a day service (Wave 2: 64.3%), community activities (Wave 2: 80.4%; Wave 3: 54.8%), further education (Wave 3: 80.7%), or respite or short breaks away from home (Wave 2: 79.3%; Wave 3: 70%).

For Cohort 1, for those participants who reported regularly receiving these services and supports pre-pandemic, there were some trends in their use of services between Wave 2 and Wave 3. For example, participants more frequently reported that they had been attending day services in person during the preceding four weeks at Wave 3 of the study compared with Wave 2 (50.3% vs. 31.7%). This was also the case for accessing community activities at Wave 3 of the study, compared with Wave 2 (37.5% vs. 6.9%), and for respite or short breaks away from home (9.3% vs. 2.1%). There were similar trends for this sub-group in Cohort 2, where it was more frequently reported at Wave 3 of the study that people with learning disabilities were attending day services (52.5% vs. 29.5%), community activities (39.2% vs. 11.1%), and accessing respite (30% vs. 20.7%) in person during the previous four weeks, compared with Wave 2. Conversely, there was a reduction in reported access to Further Education, either in person or online, for these participants in Cohort 1 between Wave 2 and Wave 3 of the study (combined 31.8% vs. 16%). This was also the case for further education for this sub-group of participants in Cohort 2 (combined 54.9% vs 19.3%).

Some differences between these sub-groups in both cohorts were evident, including the finding that people with learning disabilities in Cohort 1 who had been regularly accessing these services and supports pre-pandemic were more frequently reported to have been attending (in person and online combined) day services (combined 46% vs. 35.7%) and community activities (combined 54.1% vs. 19.5%) compared with those in Cohort 2 at Wave 2 of the study. This difference was due to people in Cohort 1 more frequently reporting accessing online activities than those in Cohort 2. The difference was not evident at Wave 3 of the study for day services (combined 55.6% vs. 53.2%), but was for community activities (combined 58.2% vs. 45.2%).

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In terms of contact with health and social care professionals, at Wave 2 of the study, people with learning disabilities in Cohort 2 who were seeing these professionals regularly pre-pandemic were more frequently reported to be receiving support (in person, via telephone, and/or online) from their psychiatrist/clinical psychologist/counsellor than this group of people in Cohort 1 (combined 39.3% vs. 27%), however this difference was not apparent at Wave 3 (combined 30% vs. 34%). People in this sub-group in Cohort 1 were more frequently reported to have social worker visits at Wave 2 of the study than people in this sub-group in Cohort 2 (combined 39.2% vs. 16.5%) but, again, this difference was not apparent at Wave 3 (combined 39.7% vs. 35.2%). The only reported difference to be stable between Wave 2 and 3 of the study for these sub-groups of participants was for contact with other therapists (e.g., speech and language therapists, physiotherapists), whereby people with learning disabilities in Cohort 2 were more frequently reported to see them in both Wave 2 and 3 compared to people in Cohort 1 (Wave 2: combined 44.3% vs. 28%; Wave 3: 45.9% vs. 18.3%).

Access to health and social care services and formal supports over time for people who did not use the services pre-pandemic

For all the adults with learning disabilities included in both cohorts who reported that they did not regularly use each service pre-pandemic, Table 3 reports how many of these people had received these formal supports in the four weeks before their interview/survey during the Wave 2 (April-May 2021) and Wave 3 (July-August 2021) data collection periods.

****INSERT TABLE 3 ABOUT HERE****

There were some differences in reported access to services between Cohort 1 and 2 for people with learning disabilities who were not regularly using these services pre-pandemic; namely, people with learning disabilities in Cohort 2 were more frequently reported to be in contact with other therapists (e.g., speech and language therapists, physiotherapists) (study Wave 2: 14.5% vs. 3.4%) and having personal assistants/support workers help them at home (Wave 2: 24.7% vs. 12.9%; Wave 3: 24% vs. 11.7%), compared with Cohort 1. Participants in this sub-group in Cohort 1 more frequently reported accessing community activities (in person and online) (Wave 2: combined 30.5% vs. 11.4%; Wave 3: 45.3% vs. 23.1%) than people in this sub-group in Cohort 2, with most of this difference at Wave 2 being due to more people in Cohort 1 reporting accessing community activities online, compared with Cohort 2 (23.6% vs. 0%).

For Cohort 1, for participants who reported that they did not regularly receive these services and supports pre-pandemic, there were some trends in accessing these between Wave 2 and Wave 3 of the study. Namely, there was a substantial increase in participants reporting that they were accessing community activities in person at Wave 3 of the study, compared with Wave 2 (37.5% vs. 6.9%); this difference was also apparent when both online and in person access were combined (45.3% vs. 30.5%). There was a trend in the same direction for this sub-group of participants in Cohort 2 (23.1% vs. 11.4%). However, the relative number of people that this was the case for was small (9 vs. 4). Further, there was an increase in the proportion of participants in this sub-group in Cohort 1 reporting that they were accessing day services in person rather than online at Wave 3 of the study, compared with Wave 2 (In person: 7.2% vs. 4.3%; Online: 0% vs. 2.8%). Participants in this sub-group in Cohort 1 also more frequently reported receiving respite or short breaks away from home at Wave 3 of the study, compared with Wave 2 (9.3% vs. 2.1%).

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Discussion

This paper presents selected data from the three Waves of the Coronavirus and people with learning disabilities study (Flynn et al., 2021a), comparing access to health and social care services over time with two cohorts of adults with learning disabilities. It was apparent that many participants in both cohorts who had previously reported regularly accessing the services/supports pre-pandemic were not receiving them during Wave 2 and 3 of the study, with a majority of participants in Cohort 1 reporting that they had not seen (in person, via the telephone, or online) any of the five health and social care professionals we asked about in the survey in both Wave 2 and 3 of the study. This was similar for people with learning disabilities in Cohort 2. Day services were not being accessed by the majority of people in both cohorts at Wave 2, but it was less frequently reported at Wave 3, indicating that day services were, perhaps, easier to access for people with learning disabilities at this time.

For people with learning disabilities in both cohorts, the increase in accessing in person day services, community activities, and respite or short breaks from home is perhaps reflective of an increase in availability/opportunities between April-May and July-August 2021, and/or an increase in people's confidence to access in person services and activities during this same period. The reduction in access to Further Education between Wave 2 and Wave 3 of the study for participants in Cohort 1 who reported in Wave 1 that they regularly attended Further Education is likely to be due to the end of academic term, rather than a decreased willingness or confidence to attend.

There is a similar pattern of results across the two cohorts and generally, more adults with learning disabilities in Cohort 2 than people in Cohort 1 were regularly using these health and social care services before the first national lockdown in March 2020, and it is therefore likely that they would have had greater health and social care needs than people in Cohort 1. Some of these differences were substantial, including for respite, going out with personal assistants/support workers, and accessing day services; all of which are likely to impact on the persons' carers as well.

These data indicate that many health and social care services were still not being regularly accessed at Wave 2 and/or Wave 3 of the study by people with learning disabilities who previously regularly accessed them pre-pandemic, although there were some trends in services and supports being accessed more between April-May and July-August 2021. These seemingly longer-lasting effects of the national and regional lockdowns were still being felt by people with learning disabilities at Wave 3 of this study, many of whom have experienced the loss or reduction of their previously regularly accessed services and supports.

Although this dataset is the largest to date examining the longitudinal impact of the COVID-19 pandemic on health and social care access for people with learning disabilities, there are some limitations to be considered. We did not give a definition of "regular" access to health and social care services when participants were asked about their service use in Wave 1, so we cannot be certain that the interpretation of "regular" access was the same across all participants. We also must acknowledge that in Wave 1 we were asking participants in both cohorts to recall service and support receipt from 9-11 months ago to determine pre-pandemic access; therefore there may be some unreliability in the recollection of some participants. However, the majority of participants in both cohorts who reported that they, or the person they supported, did not regularly receive services or supports pre-pandemic also reported at Waves 2 and 3 of this study that these services and supports had still not been accessed in the four weeks before data collection, providing some support for the reliability of these reports. It is also possible that people with learning disabilities who were not regularly receiving

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3 services and supports pre-pandemic had a change of circumstances between March 2020 and the data
4 collection periods which led to them accessing services and supports that were not previously needed.
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7 There does also seem to be a disparity in the number of participants reporting that they accessed
8 online community activities, with more people in Cohort 1 reporting accessing community activities
9 online, compared with people in Cohort 2. This is reflective of more people with learning disabilities
10 in Cohort 1 using the internet at Wave 3 of the study, compared with people in Cohort 2 (92% vs.
11 37%; Flynn et al., 2021b). People in Cohort 2 were more likely to have severe or profound learning
12 disabilities, which is an additional barrier to accessing activities online, compared with people with
13 mild or moderate learning disabilities (Chadwick, Wesson & Fullwood, 2013). This indicates that,
14 whilst the provision of online services can engage some people with learning disabilities in their lost
15 activities and services, simply having online services available does not ensure that all people with
16 learning disabilities are able to engage in their previously received activities and services. This
17 disparity in experience is likely to exacerbate existing social isolation for people with severe and
18 profound learning disabilities, and their family carers who would also have been impacted by the loss
19 or reduction of available services and activities. It must, however, be recognised that not all people
20 with learning disabilities will want to engage with online activities and services. Service providers
21 should seek to ensure equitable access, albeit perhaps not online should this not be wanted, to services
22 and activities for all people with learning disabilities in the event of future lockdowns or pandemics.
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Table 1. Adults with learning disabilities who saw each health or social care professional, or accessed each formal support, regularly before the March 2020 national COVID-19 lockdown (Wave 1 data: Cohort 1 [n=615], Cohort 2 [n=415])

| | Cohort 1 [n (%) used to regularly see/access] | Cohort 2 [n (%) used to regularly see/access] |
|---|--|--|
| GP | 264 (42.9) | 163 (39.3) |
| Community nurse | 133 (21.6) | 110 (26.5) |
| Psychiatrist/clinical psychologist/counsellor | 124 (20.2) | 93 (22.4) |
| Other therapist | 91 (14.8) | 128 (30.8) |
| Day services | 223 (36.3) | 213 (51.3) |
| Community activities | 527 (85.7) | 293 (70.6) |
| Further education | 105 (17.1) | 83 (20.0) |
| Personal Assistants/Support Workers helping them at home | 342 (55.6) | 210 (50.6) |
| Going out with Personal Assistants/Support Workers | 307 (49.9) | 263 (63.4) |
| Social Worker visits | 223 (36.3) | 129 (31.1) |
| Respite/Short breaks away from home | 65 (10.6) | 137 (33.0) |

Table 2. Adults with learning disabilities who reported regularly using each service or seeing professionals pre-pandemic who have received these formal supports in the four weeks before their interview/survey during the Wave 2 (April-May 2021) and Wave 3 (July-August 2021) data collection periods

| | Cohort 1 | | | | | |
|--|-----------------------------------|--|-----------------------|-----------------------------------|--|-----------------------|
| | Wave 2 (April-May 2021) | | | Wave 3 (July-August 2021) | | |
| | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] |
| GP (Wave 2 n=246; Wave 3 n=216) | 41 (16.7) | 74 (30.1) | 131 (53.3) | 34 (15.7) | 66 (30.6) | 116 (53.7) |
| Community nurse (Wave 2 n=120; Wave 3 n=103) | 24 (20.0) | 21 (17.5) | 75 (62.5) | 26 (25.2) | 13 (12.6) | 64 (62.1) |
| Psychiatrist/clinical psychologist/counsellor (Wave 2 n=100; Wave 3 n=97) | 5 (5.0) | 22 (22.0) | 73 (73.0) | 11 (11.3) | 22 (22.7) | 64 (66.0) |
| Other therapist (Wave 2 n=82; Wave 3 n=71) | 12 (14.6) | 11 (13.4) | 59 (72.0) | 9 (12.7) | 4 (5.6) | 58 (81.7) |
| Day services (Wave 2 n=189; Wave 3 n=171) | 60 (31.7) | 27 (14.3) | 102 (54.0) | 86 (50.3) | 9 (5.3) | 76 (44.4) |
| Community activities (Wave 2 n=444; Wave 3 n=397) | 70 (15.8) | 170 (38.3) | 204 (45.9) | 190 (47.9) | 41 (10.3) | 166 (41.8) |
| Further education (Wave 2 n=85; Wave 3 n=75) | 21 (24.7) | 6 (7.1) | 58 (68.2) | 8 (10.7) | 4 (5.3) | 63 (84.0) |
| Personal Assistants/Support Workers helping them at home (Wave 2 n=282; Wave 3 n=255) | 237 (84.0) | - | 45 (16.0) | 208 (81.6) | - | 47 (18.4) |
| Going out with Personal Assistants/Support Workers (Wave 2 n=250; Wave 3 n=220) | 194 (77.6) | - | 56 (22.4) | 182 (82.7) | - | 38 (17.3) |

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| Social Worker visits (Wave 2 n=191; Wave 3 n=174) | 18 (9.4) | 57 (29.8) | 116 (60.7) | 25 (14.4) | 44 (25.3) | 105 (60.3) |
| Respite/Short breaks away from home (Wave 2 n=49; Wave 3 n=37) | 7 (14.3) | - | 42 (85.7) | 12 (32.4) | - | 25 (67.6) |
| Cohort 2 | | | | | | |
| | Wave 2 (April-May 2021) | | | Wave 3 (July-August 2021) | | |
| | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] |
| GP (Wave 2 n=97; Wave 3 n=117) | 11 (11.3) | 39 (40.3) | 47 (48.5) | 18 (15.4) | 40 (34.2) | 59 (50.4) |
| Community nurse (Wave 2 n=72; Wave 3 n=79) | 19 (26.4) | 13 (18.1) | 40 (55.6) | 20 (25.3) | 16 (20.3) | 43 (54.4) |
| Psychiatrist/clinical psychologist/counsellor (Wave 2 n=56; Wave 3 n=60) | 7 (12.5) | 15 (26.8) | 34 (60.7) | 8 (13.3) | 10 (16.7) | 42 (70.0) |
| Other therapist (Wave 2 n=79; Wave 3 n=85) | 21 (26.6) | 14 (17.7) | 44 (55.7) | 30 (35.3) | 9 (10.6) | 46 (54.1) |
| Day services (Wave 2 n=129; Wave 3 n=141) | 38 (29.5) | 8 (6.2) | 83 (64.3) | 74 (52.5) | 1 (0.7) | 66 (46.8) |
| Community activities (Wave 2 n=179; Wave 3 n=199) | 20 (11.1) | 15 (8.4) | 144 (80.4) | 78 (39.2) | 12 (6.0) | 109 (54.8) |
| Further education (Wave 2 n=51; Wave 3 n=57) | 23 (45.1) | 5 (9.8) | 23 (45.1) | 11 (19.3) | 0 (0.0) | 46 (80.7) |
| Personal Assistants/Support Workers helping them at home (Wave 2 n=127; Wave 3 n=139) | 99 (78.0) | - | 28 (22.0) | 110 (79.1) | - | 29 (20.9) |

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| Going out with Personal Assistants/Support Workers (Wave 2 n=158; Wave 3 n=175) | 112 (70.9) | - | 46 (29.1) | 131 (74.9) | - | 44 (25.1) |
| Social Worker visits (Wave 2 n=85; Wave 3 n=88) | 4 (4.7) | 10 (11.8) | 71 (83.5) | 11 (12.5) | 20 (22.7) | 57 (64.8) |
| Respite/Short breaks away from home (Wave 2 n=92; Wave 3 n=90) | 19 (20.7) | - | 73 (79.3) | 27 (30.0) | - | 63 (70.0) |

Row percentages may not total 100% due to rounding.

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Table 3. Adults with learning disabilities who reported not regularly using each service or seeing professionals pre-pandemic who have received these formal supports in the four weeks before their interview/survey during the Wave 2 (April-May 2021) and Wave 3 (July-August 2021) data collection periods

| | Cohort 1 | | | | | |
|--|-----------------------------------|--|-----------------------|-----------------------------------|--|-----------------------|
| | Wave 2 (April-May 2021) | | | Wave 3 (July-August 2021) | | |
| | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] |
| GP (Wave 2 n=296; Wave 3 n=262) | 32 (10.8) | 49 (16.6) | 215 (72.6) | 39 (14.9) | 37 (14.1) | 186 (71.0) |
| Community nurse (Wave 2 n=402; Wave 3 n=364) | 32 (8.0) | 11 (2.7) | 359 (89.3) | 22 (6.0) | 9 (2.5) | 333 (91.5) |
| Psychiatrist/clinical psychologist/counsellor (Wave 2 n=415; Wave 3 n=368) | 5 (1.2) | 18 (4.3) | 392 (94.5) | 11 (3.0) | 13 (3.5) | 344 (93.5) |
| Other therapist (Wave 2 n=437; Wave 3 n=388) | 10 (2.3) | 5 (1.1) | 422 (96.6) | 18 (4.6) | 3 (0.8) | 367 (94.6) |
| Day services (Wave 2 n=325; Wave 3 n=290) | 14 (4.3) | 9 (2.8) | 302 (92.9) | 21 (7.2) | 0 (0) | 269 (92.8) |
| Community activities (Wave 2 n=72; Wave 3 n=64) | 5 (6.9) | 17 (23.6) | 50 (69.4) | 24 (37.5) | 5 (7.8) | 35 (54.7) |
| Further education (Wave 2 n=432; Wave 3 n=386) | 12 (2.8) | 7 (1.6) | 413 (95.6) | 4 (1.0) | 3 (0.8) | 379 (98.2) |
| Personal Assistants/Support Workers helping them at home (Wave 2 n=233; Wave 3 n=205) | 30 (12.9) | - | 203 (87.1) | 24 (11.7) | - | 181 (88.3) |
| Going out with Personal Assistants/Support Workers (Wave 2 n=265; Wave 3 n=240) | 46 (17.4) | - | 219 (82.6) | 43 (17.9) | - | 197 (82.1) |

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|---|----------------------------------|---|----------------------|----------------------------------|---|----------------------|
| Social Worker visits (Wave 2 n=332; Wave 3 n=294) | 19 (5.7) | 27 (8.1) | 286 (86.1) | 18 (6.1) | 27 (9.2) | 249 (84.7) |
| Respite/Short breaks away from home (Wave 2 n=141; n=129) | 3 (2.1) | - | 138 (97.9) | 12 (9.3) | - | 117 (90.7) |
| Cohort 2 | | | | | | |
| | Wave 2 (April-May 2021) | | | Wave 3 (July-August 2021) | | |
| | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] | Yes, in person [n (%)] | Yes, via telephone or online only [n (%)] | No [n (%)] |
| GP (Wave 2 n=113; Wave 3 n=127) | 6 (5.3) | 21 (18.6) | 86 (76.1) | 9 (7.1) | 21 (16.5) | 97 (76.4) |
| Community nurse (Wave 2 n=141; Wave 3 n=162) | 9 (6.4) | 12 (8.5) | 120 (85.1) | 18 (11.1) | 11 (6.8) | 133 (82.1) |
| Psychiatrist/clinical psychologist/counsellor (Wave 2 n=158; Wave 3 n=179) | 5 (3.2) | 8 (5.1) | 145 (91.8) | 4 (2.2) | 6 (3.4) | 169 (94.4) |
| Other therapist (Wave 2 n=131; Wave 3 n=149) | 14 (10.7) | 5 (3.8) | 112 (85.5) | 11 (7.4) | 5 (3.4) | 133 (89.3) |
| Day services (Wave 2 n=86; Wave 3 n=98) | 6 (7.0) | 2 (2.3) | 78 (90.7) | 5 (5.1) | 1 (1.0) | 92 (93.9) |
| Community activities (Wave 2 n=35; Wave 3 n=39) | 4 (11.4) | 0 (0.0) | 31 (88.6) | 9 (23.1) | 0 (0.0) | 30 (76.9) |
| Further education (Wave 2 n=163; Wave 3 n=179) | 6 (3.7) | 0 (0.0) | 157 (96.3) | 2 (1.1) | 1 (0.6) | 176 (98.3) |
| Personal Assistants/Support Workers helping them at home (Wave 2 n=85; Wave 3 n=96) | 21 (24.7) | - | 64 (75.3) | 23 (24.0) | - | 73 (76.0) |

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| Going out with Personal Assistants/Support Workers (Wave 2 n=53; Wave 3 n=59) | 10 (18.9) | - | 43 (81.1) | 15 (25.4) | - | 44 (74.6) |
| Social Worker visits (Wave 2 n=129; Wave 3 n=148) | 8 (6.2) | 10 (7.8) | 111 (86.0) | 13 (8.8) | 13 (8.8) | 122 (82.4) |
| Respite/Short breaks away from home (Wave 2 n=121; Wave 3 n=145) | 2 (1.7) | - | 119 (98.3) | 6 (4.1) | - | 139 (95.9) |

Row percentages may not total 100% due to rounding.

